ETHICS COMMITTEES

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1. Introduction.

Army regulations[3] only inferentially refer to hospital ethics committees (HEC), and provide very little guidance about the purpose, composition, processes, goals, and function of such committees:

> "The ethics panel, convened on an ad hoc basis, will be composed of at least two physicians, a nurse, a chaplain, and a representative of the local staff judge advocate. The panel exists for the patient, and in those situations where there may be some doubt concerning the propriety of a DNR[4] order, the panel will be convened to help resolve the problem if there is a lack of concurrence by the treating physicians, or members of the family among themselves or with the treating physicians."[5]

The good news is materials, articles, and books on the subject of bioethics[6] abound. In the last couple of decades, national organizations, schools of bioethics, writings and conferences, and most importantly general bioethics awareness of healthcare

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[3] AR 40-3 (15 February 1985), Chapter 19, Do Not Resuscitate Orders or "No Code" Orders. Note, however, that a revised AR 40-3 is scheduled to be effective perhaps as early as July 1999.
[4] "Do Not Resuscitate" order. While there is usually some general common understanding of the meaning of a DNR, it is best to spell out - in discussions with the patient and by writing in the chart - the specific parameters of such orders as they apply to each particular patient, or have procedures which flesh out the order, and include the understanding of the patient. For example, some patients may request a DNR, but think resuscitation only involves manual chest compressions and mouth-to-mouth resuscitation.
[5] AR 40-3, paragraph 19-2g. The composition of the HEC should be given careful consideration. The HEC may wish to include members from such areas as the Patients' Representative Office, Social Work Services, and Clinical Investigation. Members should generally be willing and interested in bioethical issues.
[6] The term "bioethics" will be used in this article to cover that concern with which most HECs struggle. The term "ethics" is sometimes used ambiguously and can lead to confusion, because the government standards of conduct provided for in the Joint Ethics Regulation (JER) (DOD 5500.7-R, 30 August 1993, w/ Change 1 through 4, 6 August 1998) are referred to as "government ethics," and "ethics counselors" refer to those who advise on the JER, not attorneys expert in counseling on bioethical issues.

personnel have flourished. That is not to say there has not been confusion, particularly with respect to what HEC are and are not.

The language quoted above would suggest HECs are called into existence intermittently and for only one purpose, discerning the propriety of a DNR. Anecdotal experience from across the Army and the nation suggests that this is a far too restrictive view of the actions and possibilities of an HEC. Nationally, it appears nearly every hospital has a HEC or will have one soon.[7] In order to comply with Army guidance, there seems to be no workable alternative to establishing a functioning HEC. Luckily, the literature is replete with articles and books on HEC, how to structure them, and any other useful topic. Suffice it to say, a hospital attorney in the Army should ensure the supported facility has a HEC and that there is an attorney on the HEC.[8]

A more complex issue concerns the role of the attorney on the HEC. Some may assume that the language in paragraph 19-2g requires the lawyer be present to provide legal advice to the HEC. That conclusion is not mandated by the language. The physicians, nurse, and the chaplain are certainly not listed so they can provide their professional services to the committee. It makes little sense, then, for the attorney to be designated to provide legal services to the committee. The attorney's expertise, experience, background, and ability to understand the legal process and bring relevant information to the committee is more solid justification for the attorney's participation.

The attorney on the HEC does not have to be the hospital's legal advisor. There are both pros and cons to having the hospital's legal advisor sit on the HEC. For obvious reasons, the selection should focus on an individual with an interest in bioethics, a willingness to develop some expertise in the area, preferably a mature attorney with some background in medico-legal issues, and an individual with some stability to provide continuity of participation. The individual selected should be dispassionate enough to understand that what may be ethically correct may not be legal, and what may be legal is not necessarily ethically correct. An ability to balance such an apparent paradox is a basic requisite for the position.

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[7] Bayley and Branford, "Ethics Committees: What We have Learned," materials of the Seventh National Conference on Ethics Committees, "Legal Counsel and the Courts: Handling Hard Cases in Health Care," 1991, pp. 495-501.

[8] "Representative of the local staff judge advocate" is sufficiently vague to allow room for flexibility in selecting this individual. The requirement does not appear to be for a judge advocate. A civilian attorney could serve. It also appears that HEC are not subject to the Federal Advisory Committee Act, 5 U.S.C. App. 2, Sections 1-15, because they are not "utilized" by the agency in the sense of the statute.

For example, the DNR policy in AR 40-3, Chapter 19 is generally agreed by practitioners to be practically unworkable and woefully out of date. An attorney member of the HEC is providing little in the way of useful service if the only advice is to follow the regulation until it is changed. On the other hand, the attorney can be instrumental in helping draft hospital policies and patient information pamphlets on such topics as DNR, withholding or withdrawing life-sustaining support, advance medical directives, patient rights, and organ transplantation.

In the same way, the attorney member of the HEC is not an advocate for the hospital or the health care team. The need is not for an attorney who will be ready to say, "I can go to court and get an order to force…" For example, in working with patients whose religious beliefs prohibit their accepting the use of blood or blood products in their care, a confrontational approach is not fruitful. The HEC is best served by an attorney who can facilitate finding an agreed treatment course that is within the bounds of medicine and acceptable to the patient or next-of-kin. This may require more education in alternative clinical practices and blood salvage/extenders than reading of court cases devoted to forcing conventional treatments on patients.

2. The Function of Ethics Committees.

Most HEC function in three primary areas: ethics consultation, education and training of the hospital staff and the patient community, and development of policy. Because Army regulations are so silent on the functions of HEC, a preliminary matter must always be the development of a clear charter for the HEC. This can be accomplished through a command memorandum or hospital standard operating procedure.[9]

Ethics consultation takes two general forms. First is the committee consultation requested by a physician, a patient, a member of the health care team, or a family member. Any of the parties involved in the care of a patient should be permitted to bring an issue to the HEC for assistance in resolution.[10] The committee using any of a number of processes will hear as much about the facts of the case as can be gathered, deliberate, and formulate its advice for the care team. This is often a complex process and must show sensitivity and compassion for all the parties involved. Many times the issues arise because of ineffective communication between the provider and the patient or

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[9] See AR 25-30, The Army Integrated Publishing and Printing Program, 15 July 1996, for information on the proper format for command policy and guidance statements.

[10] Note that HECs are not decision making bodies. They may facilitate and advise, but they do not decide care issues.

family members. In such cases the HEC can function very effectively to facilitate communication. Often, some other party needs to get involved in order for a resolution to be effected. For example, it may be useful for the HEC to involve a social worker in a case to facilitate placement of an elderly patient in a long-term care facility.

The nature of consultations before HECs is many and varied, and no two will be identical. The HEC should develop some standards by which it is available for "whole committee" consultations. Simpler, more direct cases involved in patient care may be resolved by the second kind of consultation, the "bedside" consultation. Interested and qualified members of the HEC may volunteer to work in two- or three-member teams to provide on-the-spot consultations for care teams in the hospital. They might serve on a rotating on-call basis, changing membership every week. Again a standard procedure can be developed for invoking the consulting team. Such teams are particularly useful in disposing of immediate, fairly clear issues. They may serve an important legal function as a secondary matter.

> Ethics committees may offer an attractive alternative to the courts. The judicial system may be too slow for clinical decisions. Moreover, the adversarial judicial process may polarize physicians, patients, and families, whereas ethics committees may reconcile divergent views. The 1986 New York State Task Force on Life and the Law encouraged resolving patient care dilemmas at the hospital level, rather than returning to the courts, and suggested that ethics committees might mediate such disagreements. [Footnotes omitted.][11]

It is important to recall that the very nature of HEC suggests their deliberation and recommendations are based on sound ethical principles and reasoned approaches to real-life problems. These are not dispute resolution mechanisms designed to follow custom, consensus, hospital power, or self-interest.[12]

There are several principles for the attorney to keep in mind when working on a HEC:

a. Patients are treated only to the extent of their consent.

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[11] Lo, "Promises and Pitfalls of Ethics Committees," *The New England Journal of Medicine*, vol. 317, no. 1, July 2, 1987, p. 46.

[12] Bibliographic research and assistance is available through the Georgetown University National Reference Center for Bioethics Literature (www.georgetown.edu/research/nrcbl/scopenotes/sn15.htm) and many Internet websites.

b. Physicians are not ethically obligated to provide a treatment that would harm the patient or provide no relief.

c. Decisions for patients without decision making capacity[13] should be made in accord with local law in terms of principles to be followed and the order of substitute decision makers to be observed.[14]

Continuing education and training of healthcare providers and the patient population is another responsibility of the HEC. This includes increasing the awareness within the hospital of the role and availability of the HEC, and of bioethical issues in general. The educational process may be aided by monthly classes (perhaps in a roundtable discussion format), monthly newletters, availability of bioethics materials in a specific location near the entrance to the hospital medical library and in the patient education center, and visibility of members of the HEC on other committees[15] and functions within the hospital. The area of bioethics is ever-evolving, and up-to-date materials and information are essential.[16]

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[13] "Capacity" and "competence" are two different concepts. "Competence" is a legal determination usually made by judges in a procedural setting. Decision-making "capacity" is determined by different standards by the treating physician, perhaps with the assistance of other professionals (e.g., social workers, psychologists, consulting neuropsychiatrists, etc.). The latter determination is made with respect to the present, not for all decisions and not for all treatments. A particular patient may have decision-making capacity with respect to refusing certain treatments, but not to authorizing other, more invasive procedures. The more invasive the procedure being consented to, the greater the capacity the patient needs to have in order to consent. Capacity is a very sensitive matter that should include as many facts and as much expertise as possible. Some healthcare providers may question a patient's capacity simply because the patient disagrees with the provider's treatment recommendation. Members of the HEC should be sensitive to such situations and attempt to help the provider see the situation as it really is.

[14] Sometimes the substitutes provided by law are not those that would be chosen by the care team or even the HEC. Every attempt should be made to work with the substitute decision maker and other interested family members or friends to build consensus, not litigate the power to control a patient's destiny.

[15] A medical center may find it advisable, for instance, to have the hospital attorney and the hospital director of clinical investigations be members of both the HEC and the Human Use Committee, to provide overlap and awareness between these two functions.

[16] Bioethical concepts and principles have changed dramatically over the last few decades. In the 1970s, doctors like "Marcus Welby" were considered always to know what was best for their patients, no matter what the patient thought. In the 1990s, the concept of patient autonomy, in which the patient is considered fully capable of making all of his own healthcare decisions after being fully informed by his doctor, is key. A new attorney member of a HEC may find it useful to read a current bioethics textbook, such as Biomedical Ethics, by Thomas A. Mappes and David DeGrazia, McGraw Hill, Inc, 1996, to

There are a number of matters with which a HEC can expect to deal:[17]

a. End-of-life decisions. The DNR order referred to in AR 40-3 might have been a matter of momentous concern a decade ago. The issues have expanded and become more complex as our understanding of the scientific facts, number of participants in the process, concerns for patient autonomy, and openness to HEC involvement have multiplied. Additionally, the possible decisions have increased. From straightforward, though by no means routine, questions of withdrawing and withholding life-sustaining treatment, the realm of issues has increased to include physician assisted suicide, euthanasia, pain management at end-of-life, and "rational" suicide. And depending on the healthcare facility's patient population, there can be a wide variety of cultural perspectives to understand and consider in making treatment decisions and in discussing end-of-life issues with patients.

b. Case management. With some frequency physicians and patients have difficulties in their encounters over treatment. The problems can have many and multiple sources, but often the HEC is seen as a place to seek resolution, especially as a particular HEC gains maturity and the respect of the medical staff. Often, the legal answer to a problem (e.g., something as simple as, "Who can make medical decisions for Grandpa, since he is comatose?") may be the perfectly ethical answer. Thus, the attorney may provide important input on many issues presented to the HEC. Often, parties come to the HEC wanting to force use of the hospital's legal assets to resolve what is essentially a provider or an ethical problem.

For example, it is common for providers or even HECs to want the attorney to seek a court ordered guardianship in order to get to a desired result or force next-of-kin to cooperate in a care plan. Such guardianships are seldom realistic solutions and rarely will they accomplish much that cannot be otherwise accomplished through social work services, state social or protective agencies, or constructive mediation with next-of-kin. Guardianships generally take several weeks to accomplish, even

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understand the current concepts and principles and the major areas of concern in modern bioethics.

[17] A book that may be useful in giving a "feel" for what a real-life ethics committee deals with is First, Do No Harm, by Lisa Belkin, Fawcett Books, 1994, which follows the HEC at Hermann Hospital in Houston, Texas for an eighteen-month time period in the late 1980s.

when they are unopposed. Appointed guardians[18] are of limited utility; they are most useful when the guardianship is pursued by next-of-kin with support from the hospital.

c. Organ and tissue donation. There are a number of ethical issues surrounding organ and tissue transplantation.[19] Issues of culture, personal values, and identification of decision makers cloud an otherwise highly charged subject. Often there is a tendency to impose western values on what is an endeavor without a very helpful history. With the specter of Mary Shelley's Frankenstein looming, there are always macro-issues looming (such as distribution of benefits, equity, justice). Often there are legal and ethical issues so closely intertwined, truly expert advice is needed to tease out a sensible solution.[20] The key to such issues is a sensitivity to the needs of the decision maker, understanding that those needs may cloud the wishes of the deceased.

d. Pediatric cases. These present some of the most difficult cases, because by definition the patient is never capable of making the critical decisions. Often parents are so emotionally stressed they have difficulty acting rationally. Ethical issues surrounding neonatal care may be particularly emotionally charged, because it can be difficult for all concerned to deal with end-of-life issues when thinking about newborns. Inexperienced HEC members should rely on the advice of experienced counselors in dealing with such situations. Often HECs will make no recommendations to resolve issues, but rather work with the family and care team for an extended period until they can reach consensus on an approach to care.

e. HIV and AIDS issues. Here the questions are often those of justice and equity and of futility of are. Sometimes it is

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[18] The court will frequently appoint guardians from a list of attorneys and others willing to volunteer for the role. These individuals scrupulously follow their responsibilities, but seldom are willing to engage in cutting edge ethical decisions. More importantly, they may be limited to statutory authority and be incapable of doing all that was hoped for by those seeking the guardianship.

[19] AR 40-3, Chapter 18 contains the current Army guidance on the Army's Organ Transplantation program. Note, however, that a revised AR 40-3 is scheduled to be effective perhaps as early as July 1999.

[20] Take for example the situation where a perfect donor (brain injured, well-developed, twenty-six year old male) arrives at the hospital following trauma and is brain dead within an hour of arrival. The family and organ donor organization representatives go through the excruciating decision process and determine donation will be authorized. A clerk from the medical examiner's office calls to announce the medical examiner forbids organ harvesting (despite the attending physician's assurance that nothing vital to a forensic autopsy will be compromised by harvesting the organs involved) and refuses to discuss the matter with the surgeons, the family, the hospital attorney, or the local district attorney. What is the ethics committee to do?

the provider seeking approval for what many would see as futile care (colostomy for a patient with end-stage AIDS with less than a week's life expectancy); sometimes it is the patient insisting on what the care team feels is clearly futile care. In either case, understanding and compassion are generally more useful than legal principles that announce physicians may not be compelled to provide futile care.[21] It is not uncommon to have "disciplinary" problems with patients, including AIDS patients, especially those suffering a debilitating brain or neurological disease. Their behavior often makes treatment plans difficult, and they place an unnecessary burden on clinic staffs. It is usually effective to provide such patients a list of treatment "rules"[22] in writing with the caveat that failure to follow the rules may result in exclusion from the hospital.

f. Physician assisted suicide. While this is an issue of currency in bioethics circles,[23] it has not reached the level of serious consideration in the Army Medical Department. No doubt there are anecdotal stories of physicians in Army hospitals assisting terminally ill, pain riddled patients in ending their lives. Discussions of this issue should be encouraged and HECs should obtain as much education as possible on the moral issues involved.[24] Moving to particular cases must be handled with great trepidation and sensitivity. Only one state (Oregon) has a law providing for physician-assisted suicide, and it is a very complex, highly regulated procedure. There is no basis or consensus on which to advise that physician-assisted suicide is generally accepted as morally permissible or legally approved.[25]

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[21] The literature is replete with articles addressing the controversy over futility, what it means, what is relevance is or should be. See, e.g., "Hospitals establish policies to limit futile care," *Hospital Ethics*, Sep/Oct 1993, p. 10.

[22]The rules should be worked out with the attending physician and care team. The following are examples:

1. The patient will only be seen in the clinic with an appointment obtained by calling…
2. The course of treatment prescribed includes meeting scheduled psychiatry appointments and attending/participating in weekly group therapy sessions at…
3. The patient shall not verbally abuse clinic staff; if there is dissatisfaction with appointments, waiting time, availability of physicians…; the patient may discuss the matter with the attending physician or Ms. _____ at the Patient Representative Office.

[23]See, e.g., Weir, "The Morality of Physician-Assisted Suicide," *Law, Medicine and Health Care*, Vol. 20, 1992, p. 116; "Physician-Assisted Suicide and the Right to Die with Assistance," *Harvard Law Review*, Vol. 105, 1992, p. 2021; Symposium on Physician Assisted Suicide, *Law, Medicine and Health Care*, Vol. 24, 1996.

[24]See, e.g., McCormick, "Physician-Assisted Suicide: Flight from Compassion," *The Christian Century*, Dec. 1991, p.1132.

[25]Dr. Jack Kevorkian, after being unsuccessfully prosecuted for several assisted suicides, was convicted on March 26, 1999, of second degree murder

If such an issue arises, it would be wise to discuss the matter immediately with the Staff Judge Advocate of the Medical Command.

g. Pain management. It will often be critical when patient seek assistance with committing suicide and many other types of cases to focus significant attention on pain management. It is often the fear of intractable, unremitting pain that drives patients to raise the issue of assisted suicide. Adequate pain management has not always been the hallmark of medical practice, especially where adequate management may have the double, unintended effect of hastening death. Often in the past physicians have been reluctant to prescribe effective pain management, because it might produce drug dependence in the patient. This fear can be set aside in the terminally ill patient. Clinical expertise, nursing in-put, and the patient's autonomy must be carefully considered in disposing of pain management issues.[26]

h. Macro-Bioethical issues. There are a number of larger issues less frequently brought to HECs that deserve their attention. With the advent of "powering down" of budgetary decisions, individual facility commanders are making important decisions with ethical consequences concerning distribution of assets. Is your HEC involved with that process? It should be, at least in an advisory capacity. Significant issues of equity and justice are raised in the budgetary process. Similarly, the decisions to close a clinic or department, to initiate or cease a particular patient service, or build an addition all are in part ethical decisions. Rationing of care, claims collections policies, and other business matters raise ethical concerns as well. Do not lose sight of these larger issues while dealing with the individual patients' needs.

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and delivery of a controlled substance in the injection death of Mr. Thomas Youk. Dr. Kevorkian was charged with murder in the first degree by Oakland County Circuit Court (Michigan) prosecutors for personally injecting the fifty-two-year-old Youk, a terminally-ill man dying of Lou Gehrig's disease. In the past, Dr. Kevorkian had merely assisted in the suicide of his patients by providing toxic substances, which his terminally ill patients could self-administer. Dr. Kevorkian stated that he injected his patient in this case because Youk was paralyzed and incapable of injecting himself. Dr. Kevorkian was sentenced to 10-25 years for the second degree murder conviction and 3-7 years for delivering a controlled substance. The case is on appeal, citing ineffective assistance of counsel and improper comment by the prosecutor on the defendant's Fifth Amendment right to silence.

[26]See, Federman, et al., "The Physician's Responsibility Toward Hopelessly Ill Patients: A Second Look," *New England Journal of Medicine*, Vol. 320, no. 13, 1989, p. 844; Symposium on Pain Management, *Law, Medicine, and Health Care*, Vol. 24, no. 4, 1996.

A host of other issues will insinuate themselves into HEC considerations. The attorney on the HEC should always press for more facts. Invariably, the first report of facts will be distorted. More facts will always help, as will avoiding the rush to judgment. Encourage the HEC to take as much time as possible to formulate recommendations, especially in the most critical cases. Remember that process is often as important in such cases as product. Working on an issue with the care team, the patient, the family and others may prove as valuable as coming up with some sort of recommendation. There are no magic answers in this area; always feel free to seek assistance and support from others practicing in the field. You may want to consider membership in the American Society of Law, Medicine, and Ethics (www.aslme.org) or the American College of Legal Medicine (www.aclm.org). Similarly, civilian hospitals in your area or other national or local organizations hold annual or periodic conferences on bioethics issues; your HEC should be receiving notices of these conferences (many of which provide CLE credit).